

Long-term Data Preservation and Management of EHRs

Clinical data in digital form represents a “digital library,” and inherits all the same administration and technical issues faced by digital libraries in other fields.



Overview

Electronic, health-related patient information is vital for clinical care and medical research. However, systems interoperability for preservation, storage, and accessibility of such health data has not yet been defined for electronic health records (EHRs). Technical, policy, and administrative issues facing the health IT industry include:

- What to retain and for how long
- How to handle obsolescence of hardware and software
- Interchange of information
- Cost
- Assignment of responsibility
- Standards
- Privacy
- Legal constraints
- Economics
- Data ownership

Industry Need Addressed

It is critical that preservation of clinical information is addressed or valuable and irreplaceable information will become inaccessible or disappear over time. This could lead to disastrous consequences for patient care and research value. Replacing lost data, even if possible, will entail huge costs for patients, clinicians, administrators, pharmacists, and, potentially, the entire country's economy.

NIST Approach

NIST is collaborating with the National Institutes of Health (NIH)/National Library of Medicine (NLM), the National Archives and Records Administration (NARA), the Veterans Administration (VA), and others, such as Health Level Seven (HL7), to identify best practices and support standards development for the long-term preservation and lifecycle management of EHRs. Through these collaborations, NIST is working to identify an interoperability framework which can support a wide variety of data types, data formats/records, and data delivery mechanisms, while providing technology-independent infrastructure to acquire, store, search, retrieve, migrate, replicate, and distribute EHRs over time.

Impact

Research activities enable the creation of longitudinal health records to preserve, store and permit access to clinical data potentially into perpetuity.

For additional information, please visit <http://www.nist.gov/healthcare/emerging/recordpreservation.cfm>

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